# Congress of the United States Washington, DC 20515

April 27, 2021

The Honorable Rosa DeLauro
Chairwoman
Subcommittee on Labor,
Health and Human Services
Education and Related Agencies
Committee on Appropriations
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor,
Health and Human Services
Education and Related Agencies
Committee on Appropriations
1016 Longworth House Office Building
Washington, DC 20515

#### Dear Chairwoman DeLauro and Ranking Member Cole:

As the committee begins consideration of the Fiscal Year (FY) 2022 Labor, Health and Human Services, Education and Related Agencies (Labor HHS) appropriation bill, the undersigned members of the Congressional Brain Injury Task Force, and other members of Congress, respectfully request your support for an increase in funding for programs authorized by the Traumatic Brain Injury (TBI) Act. We also request an increase for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) TBI Model Systems, administered by the Administration for Community Living.

Known as the "silent epidemic," TBI was dubbed the signature injury of the wars in Iraq and Afghanistan. Meanwhile, incidence continues to increase here at home among our nation's civilian population. From the battlefield to the football field, TBI remains a leading cause of death and disability in both adults and youth, each day taking the lives of 138 people in our country. The primary source of funding to address this growing population is provided through the TBI Act programs.

### **Centers for Disease Control and Prevention:**

The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. CDC provides states with funding for TBI registries, creates and disseminates public and professional educational materials for families, caregivers, and medical personnel. CDC plays a leading role in standardizing evidence-based guidelines for the management of TBI, linking civilian and military populations with TBI services, and educating primary care physicians and educators.

In 2013, the National Academies of Sciences, Engineering, and Medicine issued a report calling on the CDC to establish a surveillance system that would capture a rich set of data on sports- and recreation-related concussions among youth ages 5 to 21 that is not currently available. In the Traumatic Brain Injury Program Reauthorization Act of 2018 (P.L. 115-377), language was included authorizing CDC to create a National Concussion Surveillance System (NCSS). To meet this goal, we respectfully request

\$5,000,000 in the CDC budget for the NCSS to continue the work on a national surveillance system to accurately determine the incidence of concussions, particularly among the most vulnerable of Americans—our children and youth. We also request \$6,700,000 for the CDC to continue its other TBI programming.

## **Federal TBI State Grant Program:**

The TBI Act authorizes the Department of Health and Human Services (HHS) to award grants to (1) states, American Indian Consortia and territories to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with TBI. For the past seventeen years, the Federal TBI State Grant Program has supported state efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions.

In FY2009, the number of state grant awards was reduced, forcing many states that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increased funding of the program will provide resources necessary to sustain the grants for the 24 states currently receiving funding and to ensure funding for additional states. Steady increases over five years for this program will provide for <u>each</u> state including the District of Columbia and the American Indian Consortium and territories to sustain and expand state service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination, and other necessary services and supports identified by the state. This year, we respectfully request increased funding in the amount of \$12,000,000 for an additional 20 State grants, which would expand the total number of State grants to 44 bringing the total State grant allocation to just over \$19,000,000. The Federal TBI State Grant Program is authorized at \$7,321,000 currently.

Similarly, the TBI P&A Program currently provides funding to all state P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans' benefits, and students who need educational services. We request \$6,000,000 be allocated to the TBI P&A program to allow them to serve more individuals in each state. The P&A system is currently authorized at \$4,000,000.

#### **TBI Model Systems:**

Funding for the TBI Model Systems, funded by NIDILRR in the Administration for Community Living (ACL), is urgently needed to ensure that the nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers across the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury.

In order to address TBI as a chronic condition, Congress should increase funding in FY2021 for NIDILRR's TBI Model Systems of Care program to add one new Collaborative Research Project and increase the number of centers from 16 to 18. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDILRR budget. Over the next 5 years, we request a funding increase of \$15 million, currently funded at \$7.1 million, to expand the TBI Model Systems program:

- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to three, each with an annual budget of \$1 million, currently funded at \$791,950;
- Increase the number of competitively funded centers from 16 to 18 while increasing the per center support by \$200,000, each currently funded at an average of \$449,968 per year; and
- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed over their lifetime, currently funded at \$662,500.

We appreciate your consideration of these requests for the CDC, the Federal TBI Program, and the TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist states in coordinating systems, protect the rights of persons with TBI, and bolster vital research.

Sincerely,

Bill Pascrell, Jr.

Member of Congress

Don Bacon

Member of Congress

Member of Congress

# Traumatic Brain Injury LHHS-Ed Program Letter, FY22 List of Signatories April 27, 2021

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